

## ~ Special Commission on Ovarian Cancer ~

DPH Lobby 2 Conference Room

October 4<sup>th</sup>, 2016

### Meeting Minutes

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**Commission Members present:** Dr. Michael Birrer, Joyce Kulhawik, Kate Martin, Dr. Ursula Matulonis, Betsy Neisner, Lea Susan Ojamaa, Kaituscia Potier, Diane Riche, Elaine Zollo

**Commission Members unable to attend:** Alice Moore

**Guest Speakers:** Susan Gershman, Director, Massachusetts Cancer Registry, DPH; Nancy Farrell, President, Cronin Foundation

**Staff/consultant support:** Lilly Benham, DPH and Allison Hackbarth, JSI

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Meeting started with welcome and introductions. As this was the first meeting of the Special Commission on Ovarian Cancer, members introduced themselves including background, expertise and/or experience brought to the Commission. Lea Susan Ojamaa, DPH, chaired the meeting.

Group discussed one vacancy remains on the Commission. Still seeking a House appointed Medical Specialist. Recommendations can be provided.

Open Meeting Law was reviewed and overview provided. Members completed Certificate of Receipt of Open Meeting Law materials.

Statutory language creating the Special Commission on Ovarian Cancer was reviewed. Key charge is the production of a report. Focus of the report was reviewed. DPH has engaged a consultant through JSI to assist with the completion of the report. Meetings will be structured in a way to guide, inform and complete the report.

### **Presentations:**

**Susan Gershman, Director, Massachusetts Cancer Registry, DPH** presented to the group. She provided background on the Cancer Registry as well as available data on ovarian cancer in MA. Members asked questions including confirmation that histological data is collected and that MA hospitals are required to submit data to the registry. DPH does outreach to hospitals if data is not submitted. DPH produced a 2010 Ovarian Cancer Report. This will be shared with the group.

**Nancy Farrell, President, Cronin Foundation** presented to the group. The Cronin Foundation (a non-profit organization) has been one group in MA leading efforts on ovarian cancer. Ms. Farrell provided an overview of history and mission of the Foundation. The Foundation has provided

grants and activities and efforts for ovarian cancer support, awareness and research. They have helped with a MA state-wide ovarian cancer awareness campaign. Group discussed how to support these efforts.

### **General Discussion:**

The Commission is charged with completing a report and providing recommendations. DPH has engaged JSI to help the Commission meet this requirement. **Allison Hackbarth is the JSI Consultant working on the project.** Commission members discussed items to be researched by JSI to inform the report.

Group is interested in additional data including number of women with ovarian cancer that have undergone genetic testing and if we are able to collect data on lesions on fallopian tubes. Will determine if there is an existing mechanism for these data points. DPH does not collect data on use of oral contraceptives.

One of the areas of the report is how to best effectuate early diagnosis and treatment. Outreach and awareness could be directed at physicians, medical students as well as patients and families, as well as the general public. Group discussed this area with an emphasis on symptoms vs. risk factors. JSI was asked to do further research on this area before the next meeting. Members provided suggested sources. Members discussed finding a way to standardize interventions in physician office.

Data presented earlier showed a disparity in mortality to incidence ratio of Black women compared to White, non-Hispanic, women. Commission would like to know how this compares to other states. JSI to research.

Group discussed unmet needs of patients and families and how to focus this section of the report. Some of the areas discussed were psycho-social support (during and post treatment), financial needs, unique nature of ovarian cancer and availability of support services throughout the state. As part of the discussion around support and post treatment, DPH discussed the Wellness Guide for Cancer Survivors that was developed by the Massachusetts Comprehensive Cancer Prevention and Control Network's Survivorship Workgroup. Link to this resource will be distributed to members. Next Meetings:

- Tuesday, November 8 1 – 3pm at DPH
- Tuesday, January 17 1- 3pm at DPH